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Mole, Louise

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Corresponding Author:

Professor Mary Hickson, Peninsula Allied Health Centre, University of Plymouth, Derriford Road, Plymouth, PL6 8BH

Email: mary.hickson@plymouth.ac.uk

Family carers' experiences of nutritional care for people living with dementia at home: An interpretative phenomenological analysis

Louise Mole, RD, BSc (Hons)^{1,2}, Bridie Kent, RN, PhD^{2,3,4}, Rebecca Abbott, PhD², Mary Hickson, RD, PhD^{1,2}

¹*Institute of Health and Community, School of Health Professions, University of Plymouth, UK;* ²*Collaboration for Leadership in Applied Health Research and Care, South West Peninsula (PenCLAHRC), The National Institute for Health Research (NIHR);* ³*School of Nursing and Midwifery, University of Plymouth;* ⁴*Centre for Health and Social Care Innovation, University of Plymouth: an affiliated centre of the Joanna Briggs Institute, UK;*

Objectives

Few studies have captured the experiences of family carers who manage the nutritional needs of family members living with dementia at home. The identification and management of symptoms that may affect nutritional status is often reliant upon the family carer. This interpretative phenomenological study aimed to explore the experiences and perceptions of the nutritional care of people living with dementia at home from the perspectives of the family members who support them.

Method

Semi-structured interviews were conducted between October 2017 and February 2018. Participants were also asked to keep a diary of experiences for two weeks before the interview. An Interpretative Phenomenological Analysis (IPA) approach was used throughout.

Findings

Eight participants, with a mean age of 69.6 years residing in South West England were recruited and represented a range of familial roles. Following analysis, three superordinate themes were identified: ‘becoming carer and cook’, ‘changing role and relationships’, and ‘emotional eating’.

Conclusion

Family carers make food and drink decisions daily, and feel a duty to take on the responsibility for food shopping and cooking. They are conscious about ‘doing the right thing’ when it comes to providing nutritional care, and some feel uncertain about the food choices they are making, particularly regarding a reliance on convenience foods. Changes in appetite, food preferences and mealtime habits related to dementia can lead to disruption affecting the dyad. It is important that family carers and people living at home with dementia are provided with adequate support regarding identifying nutritional risks, making appropriate food and drink choices, and preventing the risk of malnutrition in the dyad.

Keywords

dementia, nutrition, family carers, interpretative phenomenological analysis, living at home

Introduction

There are an estimated 50 million people living with dementia globally (World Health Organisation, 2017). For those living with dementia at home, family carers take on the responsibility of managing health, emotional and social needs. These can become more complex and demanding as the dementia progresses, and can have profound impacts on the individual and their family (Fauth & Gibbons, 2014).

For someone living with dementia, nutritional status can be affected in many ways including changes in memory, motor skills, taste, appetite and swallow function (Ikeda, Brown, Holland, Fukuhara, & Hodges, 2002; Kai et al., 2015). The symptoms will vary amongst individuals as dementia progresses, and may also be dependent on dementia type (e.g. Alzheimer's disease or vascular dementia) (van der Linde, Denning, Matthews, & Brayne, 2014). Family carers are often the first ones to identify nutritional issues. This is one element of care amongst many others that a carer, potentially with little experience or knowledge of dementia, may have to consider, increasing the risk of elevated levels of burden and stress, which may impact upon the quality of care provided, as well as emotional wellbeing (Brodaty & Donkin, 2009).

A recent scoping review identified three important factors which relate to the nutritional care of people living at home with dementia (Mole, Kent, Abbott, Wood, & Hickson, 2018). These included the timely identification of nutritional issues, regular monitoring of nutritional status, and increased support and education for all types of carers and healthcare professionals involved with people living with dementia at home. This review highlighted that the physical and emotional complexities of the caregiving relationship, or 'dyad', can

1 affect the nutritional status of the person with dementia and that of the carer.

2 There is a paucity of studies capturing the family carer's experiences of managing the

3 nutritional needs of the person with dementia, expressed in their own terms (as opposed to a

4 set of predefined categories) (Smith, Flowers, & Larkin, 2009). The issues associated with

5 eating and drinking in dementia, as reported by family carers have been explored using semi-

6 structured interviews (Ball et al., 2015; Hua-Chen, Hui-Chen, & Jing-Jy, 2013; Silva,

7 Kergoat, & Shatenstein, 2013; Johansson, Björklund, Sidenvall, & Christensson, 2014).

8 These studies described how coping strategies have been developed by family carers to adapt

9 to feeding issues, which they found to be a significant challenge, and that little support was

10 received from healthcare professionals. The aim of this research therefore was to understand

11 the issues and concerns of family carers of people living with dementia at home relating to

12 nutritional care in the UK setting. Interpretive phenomenological analysis (IPA) was chosen

13 as the research methodology. IPA seeks to examine, as far as is possible, the perceptions of

14 the participant (Alase, 2017). However, the process also involves the interpretative activity of

15 the researcher, otherwise known as 'double hermeneutic' (Smith, Flowers, & Larkin, 2009).

16 Therefore, in-depth interpretative accounts for a small number of participants are presented

17 when using IPA, instead of a generalised account for a larger sample.

18 Methods

19 Study design

20 Semi-structured interviews were conducted with participants between October 2017 and

21 February 2018. Participants were also asked to complete a record of their experiences two

22 weeks prior to the interview using unstructured (i.e. not chronologically dependant) diary

23 entries, to support their recollection during interviews.

24 The consolidated criteria for reporting qualitative research (COREQ) checklist, was used

during the design of this interview study, which supports ensuring quality reporting of important aspects of the methods, findings, analysis and interpretations. (Tong, Sainsbury, & Craig, 2007).

Participants

Following ethical approval from the University of Plymouth Faculty of Health and Human Sciences Research Ethics Committee (16/17-778), the study was registered on the Join Dementia Research website (www.joindementiaresearch.nihr.ac.uk). Local carer groups and memory cafes were also approached and asked to advertise the study amongst their members. To be eligible for inclusion participants were: family carers providing nutritional care to a family member living with dementia at home; able to take part in a semi-structured interview; able to record diary entries; and residing in South-West England. It was not a requirement that the family carer resided with the person living with dementia, so that a variety of familial relationships were explored. Written consent was provided prior to interview, and verbal consent was also audio recorded. Pseudonyms were used to protect participant identity.

Eight family carers volunteered to take part in the study and were either a spouse or child of the person with dementia (Table 1). The average time since diagnosis was 4.1 years, and the average age of family carer was 69.6 years.

Table 1. Participant demographics

Pseudonym of family carer (age, years)	Sex (M/F)	Relationship to person being cared for	Type of dementia	Number of years since diagnosis (if known)
Anne (66)	F	Daughter caring for Mother	Vascular Dementia	12
Sarah (48)	F	Daughter caring for Father	Alzheimer's Disease	3
Paul (77)	M	Husband caring for wife	Alzheimer's Disease	unknown

Jeff (55)	M	Son caring for Mother	Vascular Dementia	2
Joyce (69)	F	Wife caring for husband	Alzheimer's Disease	2
Tony (79)	M	Husband caring for wife	Alzheimer's Disease	4
Stan (90)	M	Husband caring for wife	Alzheimer's Disease	2
Keith (73)	M	Husband caring for wife	Alzheimer's Disease	4

Data collection

Participants were interviewed at their own homes or on University premises according to their preferences. Interviews lasted between 16 and 53 minutes, and were audio recorded and transcribed verbatim. An interview schedule was developed and piloted, and used for prompting where necessary. Topics included exploring the type of nutritional care participants provided, how they cope providing nutritional care, and what they felt would support them. Blank diary templates (see supplementary file 1) were sent to participants prior to the interview for recording mealtime experiences, and were transcribed prior to analysis. Participants were asked to record thoughts around eating and drinking, and descriptions of mealtimes that they felt were particularly positive or challenging. Some participants referred to diary entries during the semi-structured interviews, using them as a prompt to provide further explanation and meaning. Some participants did not use the provided template, but diarised entries in their own preferred format. These were still included for analysis.

Analysis

Data were analysed in accordance with an IPA methodology by LM using NVivo 11 (QSR International, 2017) to aid coding and organise emergent themes. Each transcribed account and diary was read and re-read whilst listening to the semi-structured interview recording,

ensuring that any new ideas and insights were generated (Hunt & Smith, 2004), and detailed notes on semantic content and language use were made. These collectively formed a new set of ‘source notes’ (Pietkiewicz and Smith, 2014). An iterative cycle was then taken to condense the notes into a few words which captured the central meaning of the participants’ lived experience, from which themes were formed (Alase, 2017). Connections across themes were then identified before the next participant account was approached separately and the themes that emerged from the previous case were ‘bracketed’ (Smith et al., 2009). A ‘break’ between analysing participant accounts and use of a reflexive diary supported the bracketing process. Bracketing enabled the researcher to place attitudes and assumptions to one side, and focus on the participants account (Fischer, 2009). Once all accounts and diaries had been analysed, patterns across these were investigated, and sub-themes emerged. Super-ordinate themes were developed from the sub-themes that captured the shared experiences of the participants. These super-ordinate themes are constructs that apply to all participants, but may manifest in different ways within individual participant accounts (Smith et al., 2009). This systematic approach ensured traceability of the development of themes from participant’s original accounts and diaries. IPA provided an open, adaptable approach that enabled deeper understanding of participants’ experiences, particularly of those who may be in greatest need of support (Pringle, Drummond, McLafferty, & Hendry, 2011).

Author’s perspectives

LM led the interviews, transcription and analysis and kept a reflective diary throughout the process. The research team have clinical and qualitative research experience in the field of dementia and nutrition, and LM is a registered dietitian. Although LM’s profession was not communicated to participants prior to the interview, it was not purposively concealed, and emerged during some conversations. This enhanced discussions about the participant’s experiences of following nutritional guidelines and the challenges associated with this.

Findings

Three super-ordinate themes were developed by identifying patterns between sub-themes. These represent the interpretation of how participants experienced providing nutritional care to a family member with dementia (see table 2).

Table 2. Superordinate themes with sub-themes

Becoming carer and cook	Changing role and relationship	Emotional eating
<ul style="list-style-type: none">• Adapting food provision• Dietary changes for all• Routine rules• The carers experience	<ul style="list-style-type: none">• Evolving relationship• Relationship strains• Carer is now head chef• Taking full control	<ul style="list-style-type: none">• Muddling through mealtimes• Learning to adapt diet strategies• Food guilt

These super-ordinate themes represent the complexities involved in supporting a family member with dementia, and how carers strove for balance between daily ‘dilemmas’ and the positive aspects of dementia. They described how, as they transitioned into a caring role, their relationships with the person with dementia changed, particularly around mealtimes. These changes caused strains between dyads, with the carer accommodating personality changes of their spouse or parent. Roles were often ‘reversed’ in both a practical (e.g. taking on responsibility for cooking meals), and emotional sense (e.g. putting spouse or parent’s needs first). This ultimately resulted in the carer feeling responsible, and taking control of the person with dementia’s needs, such as making decisions about food. The transitional journey of becoming a carer for someone living with dementia, and the impact that this had on nutrition care are represented by the themes. The super-ordinate themes epitomise the increase in the emotional burden carers took on, often without choice, which involved feelings of constant guilt and worry about ‘doing the right thing’, particularly where

1 nutritional care was concerned. Nutritional care can become subsumed within the
2 encompassing carer role, with priority given to other issues such as dealing with forgetfulness
3 and personality changes. Each super-ordinate theme is presented in detail, with supporting
4 excerpts from the interviews and diary entries.

5 ***Becoming carer and cook***

6 Becoming a 'carer' was a role that caregivers found themselves taking on without choice.
7 This transition often happened quickly. This meant that family members did not have time to
8 rationalise their new role, and how this was juxtaposed with the role of spouse or child. As
9 well as the caring role, participants also took on (or maintained) the role of cooking for the
10 family. Thought needed to be given to selecting food, preparing it, and presenting it to the
11 family member with dementia.

12 Carers described how they felt they had little option or choice regarding caring for a family
13 member. This dissolution of choice affected participants (often emotionally) and was
14 prevalent in their accounts.

15 'Yeah, but you have to, don't you? It's - I can't not do it ... I thought I could cope, and I
16 think you do cope because you have to, when he's here.' (Joyce, interview)

17
18 'Well, she doesn't remember I suppose how to do things, or she's become reliant on me
19 to do it ... it's okay. I've gotten used to it. It's what I've got to do.' (Jeff, interview)

20 Allowing the person with dementia to have choice over what they ate was particularly
21 important for Anne, who was keen to implement her mother's own views expressed at a time
22 before dementia. It was important to her to make that memory a reality, as her mother was
23 unable to do so. Anne endeavoured to 'liberate' her mother's diet, and not impose
24 restrictions.

1 'My mum said at the time when people are old, they should be allowed to eat what they
2 like ... So, I have that memory in my mind. So, I give her what she likes ... if she's not
3 hungry, she might have a bit of cake, and I don't care because it's what she wants.'
4 (Anne, interview)

5 Routine was perceived as an essential component of effective care, and was described by
6 carers as a positive achievement or something to strive towards. It was a success criterion of
7 their new role, which brought structure, reducing the likelihood of unplanned and unexpected
8 events. Food shopping was viewed as a new routine adopted by male carers; however, the
9 women with dementia were purposefully excluded from this task as their presence was
10 perceived as a hindrance. This suggests that these carers preferred to complete these tasks
11 rapidly and see them as something that 'needed to be done'. The person with dementia was
12 excluded from this routine task, even if they had spent many years doing the food shopping
13 for the household, and perhaps found the task enjoyable.

14 'Got into a routine of doing things. ... I go and do the shopping on a Friday, but I don't
15 take her with me because she was wandering off and stuff, so it's quicker, easier for me
16 to just go and do it on my own and come back and pack it away.' (Jeff, interview)

17
18 'It's difficult in a supermarket. I prefer to go shopping by myself now, because that sorts
19 that.' (Paul, interview)

20
21 Dementia can result in feeling a loss of independence for both the person living with it and
22 the family carer. Ironically, even though the carer may decide to take away an element of
23 independence from the person with dementia (e.g. revoking their driving license), they
24 experienced a loss of their own independence as a result (e.g. having to give up hobbies).

25 'Oh, I'm feeling doors closing all the time ... that's the sort of thing we were doing only
26 four or five years ago. That's all tailed off now.' (Keith, interview)

1 'I used to rise early and do stuff before Emily got up. Now am constricted in time to do
2 my things due to sorting Emily. Have to attend to my and Emily's routine medical
3 challenges, so suffer from as less time for physical activity and keeping up with friends
4 and relations. Frustrating.' (Paul, diary)

5 Carers learnt to make adaptations to help them cope in difficult situations when supporting a
6 family member with dementia. As their role evolved, they created strategies and developed
7 routines in an effort to reduce the time spent in caring activities. They often needed to work
8 around the person with dementia's routine, which took precedence. An example of an
9 adaptation is mealtime planning, where shortcuts were considered necessary to ensure that
10 there was minimal interruption to important routines.

11 'I'll try and cook properly a couple of days and other days it will be quick and easy stuff,
12 just because it's quick and easy ... Because mum likes watching all the news quite a lot
13 ... I've got to fit it around that ... I've got to get out and do that while that's going on. Try
14 and fit in with her really.' (Jeff, interview)

15 The role of family carer was complex, and involved balancing many practical elements as
16 well as making moral decisions. Food shopping was an example where family carers took a
17 'task-based' approach in order to 'get things done quickly'. Routine seemed to help family
18 carers, and they made adaptations to cater for the person they were caring for.

19 ***Changing role and relationships***

20 The caring role can result in unforeseen changes within relationships, and this presented
21 difficulties for carers to deal with. The carer and familial relationship roles did not seem to
22 exist harmoniously and there was unease associated with the term 'carer'. Although caring
23 for a family member resulted in taking more control, more responsibility and becoming the
24 primary decision maker, participants felt demoted and undervalued.

25 The person with dementia became the primary concern, and the carer's needs were de-

1 prioritised. This presented a challenge for carers in terms of how they accepted and managed
2 this disruption, particularly around food provision, to what was once an equal marital
3 partnership.

4 'I just find it up until 18 months ago, I couldn't take this word carer. It was just too alien.
5 She was my wife. I still find it difficult comprehending this term carer. But it's a fact.
6 One is caring for or helping or looking after or whatever.' (Tony, interview)
7

8 'Anybody who we have a contact with where necessary knows that she's got dementia.
9 So as soon as we see anybody it's always, how's Maureen? Then if it's about me it's, how
10 are you managing with Maureen?' (Stan, interview)

11 This demotion was a source of frustration for carers, as they felt as though their family
12 member's dementia diagnosis took precedent. They argued, in fact, that when considering
13 changes to nutritional intake, they recognised more changes in their own diet than the person
14 they are caring for. These changes were not always seen as positive, and affected the quality
15 of the mealtime experience for the carer.

16 'But, yes, my mum struggles because things that they've always had for meals, he won't
17 touch anymore. So, if she bought lamb chops or something, he won't touch that any
18 more. He doesn't like it ... So now she finds herself eating quite blandly, quite boring,
19 not as much.' (Sarah, interview)
20

21 'Before mum came to live with us we never ate any 'convenience' food or anything from
22 a packet.' (Anne, diary)

23 Family members who are caring for a parent felt duty bound to take on this role, and they
24 recognised an element of role reversal taking place. The adult child recognised that the
25 parent once met their physical and emotional needs and felt obliged to do the same.

26 'Well, I'm flesh and blood so I've got to do it. She's brought me up when I was a child and
27 baby and all that. A little bit of role reversal I suppose. I just carry on looking after her,

1 looking after her interests.’ (Jeff, interview) This care role extended further, ensuring that
2 meals were prepared exactly how the person with dementia wanted them. Taking the effort
3 to meet these standards did increase the amount of food the person with dementia ate,
4 alleviating concerns for the family carer.

5 ‘Mum likes mayonnaise with many things and is fussy about sandwiches being just how
6 she likes them – it makes the difference between her eating or not eating something if
7 you get it right’. (Anne, diary)

8 The role reversal can impact upon the person with dementia as well as the carer. Men may
9 once have had the traditional role of ‘head of the family’, and women may have taken the
10 lead role during special occasions (e.g. Christmas lunch). Their confidence to continue in
11 this role can be diminished by dementia. Where family meals were once an occasion to look
12 forward to, these no longer take place. The disappearance of this positive family ‘ritual’ can
13 affect the emotional significance of mealtimes for the whole family, as well as affecting
14 nutritional intake.

15 ‘But now he just doesn't have an interest in food like he perhaps used to. He used to like
16 it when we had a roast dinner and he'd carve the meat, and he can't do any of that
17 anymore. I don't know whether it's his own knowledge that he can't do things to help or
18 whether it's just the fact he doesn't have an appetite anymore.’ (Sarah, interview)

19
20 ‘[She] used to do all the cooking. She's done Christmas lunches and things like that. She
21 hasn't got a chance of doing them now. She can't sequence anything and everything. She
22 wanders off and leaves things.’ (Paul, interview)

23 For husbands who are caring for their wives with dementia, there was a marked transition in
24 the role of food provider for the household. This was embraced with varying degrees of
25 experience, but they felt a sense of responsibility to ensure an adequate and balanced
26 nutritional intake.

1 ‘On retiring, I took over some of the things but basically, she was head cook and I was
2 bottle washer and vegetable peeler and so on ... I decided I'd have to take over the
3 cooking at some stage, so the idea in my mind was that I would gradually take over some
4 of the meals each week from her, but somehow it clicked in her mind and it became me
5 all the time, which is fine, you know. I'm happy enough doing that. So, I do the
6 shopping, the cooking, all of that sort of stuff.’ (Keith, interview)

7 Conversely, where women cared for husbands with dementia, although they maintained their
8 traditional role of main food provider, this was diminished as a result of their husband's
9 change in food preferences. Where once they held the matriarchal role in terms of providing
10 food for the family, their efforts were perceived to be unappreciated and this made them feel
11 undervalued and redundant. Sarah noticed this with her mother who lives with her husband
12 who has dementia.

13 ‘... but my mum feels a bit, well it's all microwave meals. She doesn't feel like she's
14 involved in the cooking there, really ... It's been almost her role to do that and seeing that
15 potentially [Dad's] not, I suppose appreciating is the wrong word, but he's pushing things
16 away when she's gone to the effort to... She feels very down about it herself ...’ (Sarah,
17 interview)

18
19 When a family member became a carer for someone with dementia, they felt that their needs
20 were often de-prioritised, particularly with regards to their own diet. They felt obliged to
21 make adaptations to meals for the benefit of the person with dementia, but not necessarily
22 themselves. Where the person with dementia may have particular requirements regarding
23 food, these were met without question in the hope that they were more likely to consume
24 more. Traditions involving food were affected by matriarchal and patriarchal role changes,
25 which saddened family carers.

1 *Emotional eating*

2 Having a family member diagnosed with dementia brought daily food and drink dilemmas,
3 which were sometimes difficult for family carers to manage. These predicaments were
4 characterised by the emotional impact they had upon the carer, particularly when they felt
5 that an important component of their relationship had been lost.

6 Monitoring fluid intake was an example that one carer, Tony, used to explain how he now
7 needed to oversee how much his wife drinks. Whilst recalling the example, he described how
8 his wife no longer remembered how he takes his cup of tea which upset him. This illustrates
9 how dementia can have a profound impact upon daily tasks that are often taken for granted.

10 ‘She enjoys a glass of wine in the evening. But I’ve got to watch her a little bit now. She’s
11 always been very much a one glass in the evening and now I see she will refresh that
12 glass. I’m just a bit conscious of that. I’ll just keep an eye on that. Because I don’t think
13 she realises she’s had a drink and that’s the dilemma. Same with tea. She’ll constantly ask
14 about - and would you believe it, after 54 years of marriage, she asked me, do you take
15 sugar, Tony, in your tea? It hurts actually.’ (Tony, interview)

16 Carers were conscious about ‘doing the right thing’, whilst trying to eliminate a guilty
17 conscience about making their family member unhappy in the process. This was particularly
18 applicable to decisions regarding food, where a particular food that was deemed by the carer
19 to be ‘unhealthy’ in terms of nutritional content, may also bring pleasure and joy to the
20 person with dementia. ‘So, I’m conscious of that. Should I be buying these things where she -
21 like biscuits and things of that nature. But she obviously enjoys it. So, I’ve got a dilemma
22 there in terms of should I get this or shouldn’t I? Should I hide it away or shouldn’t I?’ (Tony,
23 interview)

24
25 Balancing the feelings of guilt with providing a healthy diet for the person with dementia
26 led to frustration for the family carers. ‘So I don’t know, from a nutritional point of view,

1 it's trying to get the balance right and especially - even if you try and put a nutritionally
2 balanced meal in front of him, he might not eat it. So we can try and give him things that
3 we think he'd like.' (Sarah, interview)

4 Amongst the difficult aspects of caring for someone with dementia, carers recognised the
5 positive components of their role. Some mealtimes brought joy and humour, providing light
6 relief in an otherwise challenging environment. Carers who recognised positive aspects of
7 their situation tended to feel that they were coping better. They strove to maintain a positive
8 demeanour despite their situation, and were more accepting of the caring role.

9 'She likes potatoes but she doesn't like them in the pie. So, we always have this, is this
10 one of those Yorkshire things? Where are the potatoes? In the pie? What, in the pie?
11 (laughter) Every time, because of the dementia. Every time. It just makes us laugh.'
12 (Anne, interview)

13 The nutritional care a family member provided to a loved one with dementia was
14 underpinned by a range of emotions. They tried to manage these emotions whilst feeling that
15 they had to supervise the food and drink intake of the person they are caring for. They tried
16 to balance feelings of guilt regarding the nutritional value of the food they provided, whilst
17 wanting to ensure the person with dementia still enjoyed food and drink. Amongst the
18 negative emotions, there was lightness and fun in mealtimes shared with someone with
19 dementia.

20 Discussion

21 The aim of this study was to explore the family carers' experiences, expressed in the
22 participants' own terms, providing an alternative view to a clinical perspective of nutritional
23 care in dementia. To the best of our knowledge, these findings contribute the first detailed
24 interpretative phenomenological account of the experience and perceptions of nutritional care
25 for those living at home with dementia based on family carers' own descriptions. The

1 personal accounts highlight three superordinate themes central to this experience.

2 There is increased responsibility that comes with caring for a family member with dementia,
3 particularly where nutritional health is concerned. Convenience foods were used by some as
4 a coping strategy to meet the time demands of fitting into routines, as well as for those carers
5 who were inexperienced with cooking. These foods were viewed by carers as sub-standard,
6 and concerns expressed over whether they were providing adequate nutrients. There is
7 limited research regarding the nutritional adequacy of convenience food for people living
8 with dementia; however, some studies have included home-dwelling older adults as
9 participants, also finding that this group tend to associate negative meanings with
10 convenience food (Peura-Kapanen, Jallinoja, & Kaarakainen, 2017). Although a reliance on
11 foods such as ready-meals may not provide adequate nutrients to meet nutritional
12 requirements (Howard, Adams, & White, 2012), they remain an important source of nutrition
13 for many vulnerable older adults. Dietitians and nutritionists should be involved during
14 ready-meal formulation, as well as acting in an advisory capacity to support appropriate
15 choice of meals, which would be a potential method of addressing nutritional deficiencies in
16 this population (Hoffman, 2017).

17 To deal with the day-to-day tasks that caring for a family member with dementia involves,
18 many carers rely on a routine or task-based model of care provision. Food and drink
19 becomes a function and any emotional attachment lost. Within the nursing profession, task-
20 based care is perceived as unable to fulfil true person-centred care (Sharp, McAllister, &
21 Broadbent, 2018). Relationship-based care is a model of nursing care delivery that focuses
22 on the care provider's relationship with the care recipient, with themselves, and with
23 colleagues (Koloroutis, 2004, p. 4). Family carers could be supported to provide elements of
24 relationship-based care, which could result in improved health outcomes for the carer and

1 person being cared for. This may enable food to be enjoyed together as part of the
2 relationship, rather than a cause for concern.

3 Carers expressed how mealtimes had become frustrating, due to behaviour changes of the
4 family member with dementia. The severity of behavioural changes in people with dementia
5 may predict an increase in feelings of ‘role overload’ amongst family carers (Gaugler, Davey,
6 Pearlin, & Zarit, 2000). The balance between wanting to provide nutritious meals, but also to
7 ensure that the person with dementia continues to enjoy food has been identified in other
8 studies involving family carers (Keller, Edward, & Cook, 2006). Mealtimes for these carers
9 are at risk of becoming an occasion that is feared, or even avoided. This is of particular
10 concern, as mealtimes have been shown to provide rich opportunities for social interaction
11 that can be supportive for someone with dementia (Keller, Martin, Dupuis, Reimer, & Genoe,
12 2015). Family carers were upset that the person with dementia no longer wanted to take the
13 lead role in family occasions involving food. This could be explained by the changes caused
14 by dementia, such as struggling to remember meaningful roles (Genoe et al., 2010). Male
15 carers caring for female relatives, describe how they have taken full control of food provision
16 in the household, including shopping for food. It has been reported that they do not feel
17 obligated to take on this role, rather that it is an opportunity to reciprocate care (Atta-Konadu,
18 Keller, & Daly, 2011). This activity rarely involved the person living with dementia, due to
19 carers feeling stressed and frustrated if they were present. Engaging in everyday tasks
20 however, such as food shopping, can promote continuity as well as having positive impacts
21 on personhood and quality of life (Phinney, Chaudhury, & O'Connor D, 2007). Allowing
22 someone with dementia to continue engagement in domestic activities can also improve
23 wellbeing and is an example of relationship-based care, where family carers play a pivotal
24 role in facilitating this in the own home setting (Chung, Ellis-Hill, & Coleman, 2017).
25 Family carers require support with involving a family member with dementia in everyday

1 tasks such as food shopping or cooking. This would also be an opportunity to provide
2 guidance regarding the selection and preparation of suitable food choices that meet the dyads
3 nutritional needs.

4 Some family carers noticed changes in their own diets as a result of the dietary changes of the
5 person with dementia. These changes were not always viewed as positive; however, they
6 accepted them as part of the caring role. The increased burden associated with caring for a
7 family member, has been found to predict weight loss in people with Alzheimer's disease
8 (Bilotta, Bergamaschini, Arienti, Spreafico, & Vergani, 2010; Gillette-Guyonnet et al., 2000).
9 Similarly, a positive correlation has been identified between the malnutrition risk of people
10 living with Alzheimer's disease and their family carer (Rullier, Lagarde, Bouisson, Bergua, &
11 Barberger-Gateau, 2013; Tombini et al., 2016). Researchers and healthcare professionals
12 should consider not only the nutritional care for the person living with dementia, but also that
13 of the family carer.

14 Considering nutritional needs is one element in the myriad of caring duties for someone with
15 dementia. Progressive loss of cognitive function leads to additional support being required
16 with Activities of Daily Living (ADL's): bathing, dressing, grooming, toileting, walking, and
17 eating (Prizer & Zimmerman, 2018). As highlighted in the present study, some family carers
18 take a 'trial and error' approach to adapting diet strategies in an attempt to meet the
19 nutritional needs of the person with dementia. This approach has also been found to be taken
20 with wider aspects of care (Gaugler, Kane, Kane, & Newcomer, 2005). Eating disturbances
21 could be argued to be one of the more complex care needs, as it can be impacted by
22 functional, cognitive, and behavioural symptoms of dementia, although is often referred to as
23 a single symptom, which could undermine the overall impact (van der Linde, Denning,
24 Matthews, & Brayne, 2014).

Dyadic multicomponent interventions have been explored by some studies, and could improve carer burden, and relationship quality compared with carer-focused interventions (Laver, Milte, Dyer, & Crotty, 2016; Moon & Adams, 2012). Nutritional interventions focused on supporting family carers and people living at home with dementia have been explored and shown benefits short-term (Mole et al., 2018). Although no studies have focused on adherence to dietary strategies for people with dementia, older adults who have experienced support from others have described developing a liberated approach to eating and drinking which has enabled them to maintain healthy behaviours (Greaney, Lees, Greene, & Clark, 2004). Liberation of diet for people living with dementia is an area that warrants further exploration, particularly as dietary preferences can change with associated changes in the person with dementia.

Strengths and Limitations

This is the first study to report the experiences of dementia on nutritional intake from carers of people living with dementia at home in the UK. Using a diary method combined with semi-structured interviews enabled a deeper understanding of the caring experiences encountered by family carer's regarding nutritional care. However, there are disadvantages to using a diary method, including the time burden placed upon already busy carers, and the reliance upon participants having the appropriate literacy or technological skills. Some participants kept very thorough diaries (and reported that they found the process cathartic), however others were unable to keep a diary due to time constraints. Caregivers were mainly recruited through the Join Dementia Research network (www.joindementiaresearch.nihr.ac.uk) and therefore already had an interest in taking part in dementia research, which could have imparted volunteer bias. The duration of some of the interviews may be considered short for a phenomenological study. This was due to the interviews reaching a natural end, with no new accounts being provided by participants.

1 Finally, this study only explored the family carer experience of mealtimes. The results
2 therefore do not give a full description of the experience for the dyad, which could be
3 explored further by including the person with dementia in the interviews.

4 Conclusion

5 This study presents detailed interpretative phenomenological accounts of the experience and
6 perceptions of nutritional care for those living at home with dementia based on family carers'
7 own descriptions. The essence of this phenomenon is captured within three superordinate
8 themes: '*becoming carer and cook*', '*changing role and relationships*' and '*emotional*
9 *eating*'. As family carers transition into the role of carer, they make difficult decisions daily
10 (including food and drink choices). They may decide to exclude the person with dementia in
11 activities such as food shopping, which could otherwise be a beneficial and meaningful
12 activity. Dementia-related changes in appetite, food preferences and mealtime habits can
13 lead to disruption and frustration for carers, which can affect their own nutritional intake.
14 Family members feel that it is their duty to take control of food provision, regardless of the
15 type of relationship with the person with dementia. They are conscious about 'doing the right
16 thing' when it comes to providing nutritional care, and some feel uncertain about the food
17 choices they are making, particularly regarding a reliance on convenience foods. The
18 findings reinforce the importance of ensuring family carers and people living at home with
19 dementia are provided with adequate support regarding identifying nutritional risks, making
20 appropriate food and drink choices, and preventing the risk of malnutrition in the dyad.
21 Healthcare professionals may be best placed to provide this support, and future research
22 should focus on their role in this context.

23 Abbreviations

24 CLAHRC Collaboration for Leadership in Applied Health Research and Care

COREQ consolidated criteria for reporting qualitative research

IPA Interpretative Phenomenological Analysis

NIHR National Institute for Health Research

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1 Supplementary file 1 – Blank diary templates

Date:	Time:
<p><i>Please write about any mealtime experiences, eating/drinking or appetite issues, or other concerns, thoughts or emotions regarding nutrition here.</i></p>	
Date:	Time:
<p><i>Please write about any mealtime experiences, eating/drinking or appetite issues, or other concerns, thoughts or emotions regarding nutrition here.</i></p>	